



A multicenter study of the patient's perspective:

The first Parkinson's Disease Pain Questionnaire (King's PD Pain Quest)

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OBJECTIVE: To develop and validate an "easy to use" novel clinical self-completed Parkinson's specific pain questionnaire (complimentary to the King's PD Pain Scale)

BACKGROUND:

- Pain is an under-explored and poorly characterised non-motor symptom of Parkinson's and a key determinant of quality of life.¹
- We have recently validated the first pain scale specific to PD (King's PD Pain Scale).²
- There are currently no validated patient completed tools to empower patients to self-declare pain related symptoms.

Demographics	Patients	Controls
Number	236	196
Male gender: number (%)	141 (59.7%)	117 (59.7%)
Age (yrs) *	65.0± 11.0 (29-88)	64.9± 10.3 (30-89)
Education (yrs)*	14.2± 3.8 (4-24)	14.6± 4.0 (6-26)
Duration of Disease (yrs)*	5.3± 5.0 (0-26)	n/a
Hoehn & Yahr Stage: median (range)	2.0 (1-5)	n/a
Levodopa equivalent daily dose (mg)*	596.8± 441.4 (0-2550.0)	n/a
	*mean± SD (range)	

METHODS:

- In a cross-sectional, open, multicentre pilot validation study of the novel PD Pain questionnaire (King's PD Pain Quest), we collected data from PD patients with otherwise unexplained pain and from controls without PD.
- The King's PD Pain Quest was developed with help of an expert patient group, based on the King's PD Pain Scale, addressing the same items as the scale with simple "yes" or "no" answers to 14 questions in lay English, understandable by patients and carers.

REFERENCES: ¹ Wasner G, Deuschl G. Nat Rev Neurol 2012;17(8):284–29
² Ray Chaudhuri K, Rizos A. Mov Disord 2015, in press

KING'S PD PAIN QUEST

Patient ID No: _____ Initials: _____ Date of birth: _____
 Date of assessment: _____ Male Female Centre: _____

PAIN IN PARKINSON'S

The movement symptoms of Parkinson's are well known. However, other problems like pain can occur as part of the condition or its treatment. It is important that the doctor knows about the specific type of your pain, particularly if it is troublesome for you.

Several types of pain are listed below. Please:

- Tick the box "Yes" if you have experienced this particular type of pain during the past month.
- If you have not experienced the type of pain in the past month tick the "No" box.
- The doctor or nurse may ask you some additional questions to help you decide.

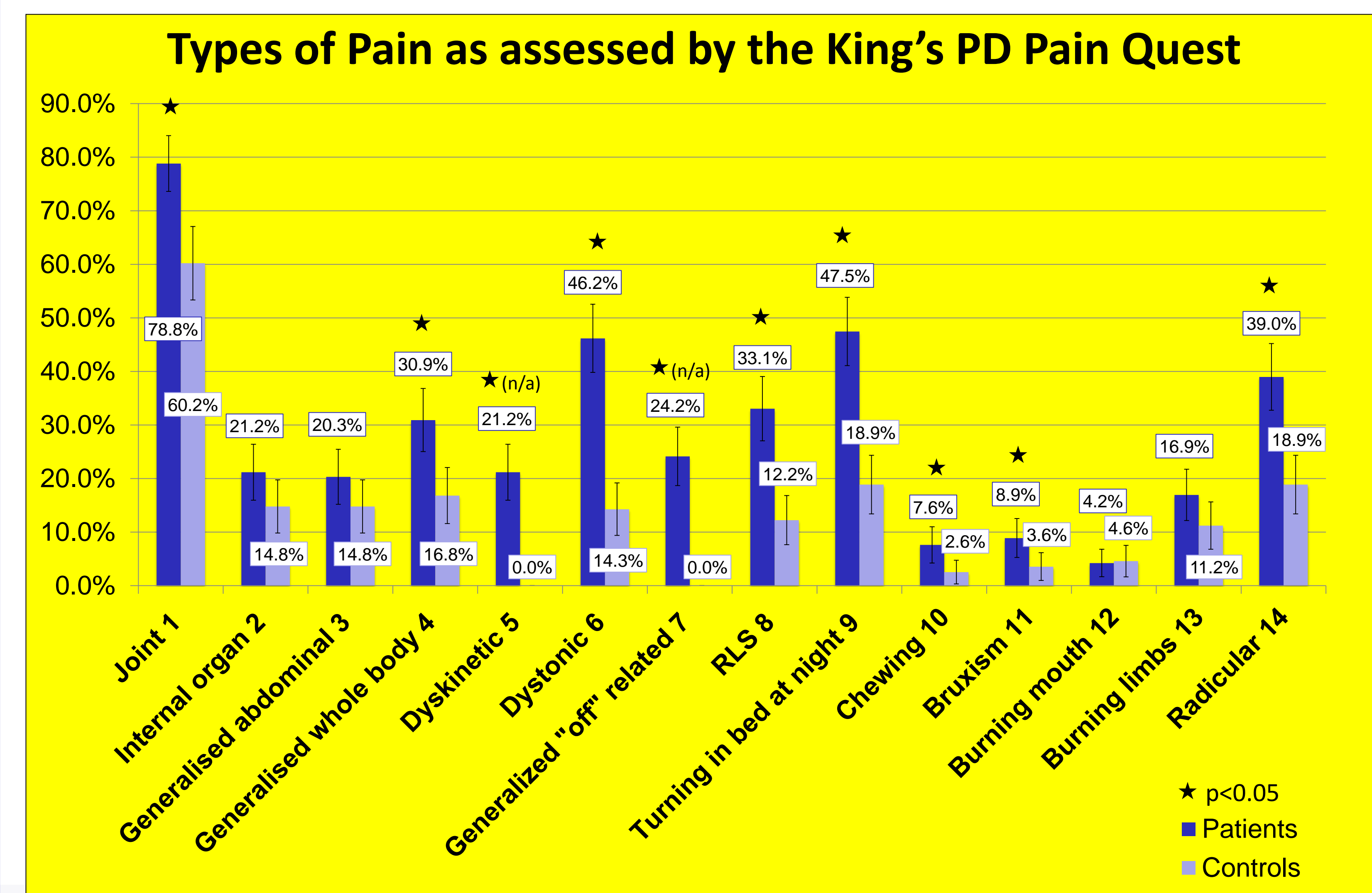
Please note that this questionnaire only relates to the pain you experienced in the last 30 days.

HAVE YOU EXPERIENCED ANY OF THE FOLLOWING IN THE LAST MONTH?

	Yes	No
1. Pain around the joints (including pain related to arthritis)	<input type="checkbox"/>	<input type="checkbox"/>
2. Pain related to a specific internal organ (for example, pain around the liver, stomach or bowels)	<input type="checkbox"/>	<input type="checkbox"/>
3. Generalised non-specific pain in your stomach area.....	<input type="checkbox"/>	<input type="checkbox"/>
4. Non-specific pain deep within the body: a generalised constant, dull, aching pain.....	<input type="checkbox"/>	<input type="checkbox"/>
5. Pain related to abnormal involuntary movements (dyskinetic pain)	<input type="checkbox"/>	<input type="checkbox"/>
6. Painful muscle cramps in a specific region during "off" periods (when your medication is not working).....	<input type="checkbox"/>	<input type="checkbox"/>
7. Generalised pain during "off" periods (pain in the whole body or areas that are not affected by muscle cramps).....	<input type="checkbox"/>	<input type="checkbox"/>
8. Pain related to jerking leg movements during the night or an unpleasant burning sensation in the legs which improves with movement (restless legs syndrome)	<input type="checkbox"/>	<input type="checkbox"/>
9. Pain related to difficulties when turning in bed at night	<input type="checkbox"/>	<input type="checkbox"/>
10. Pain when chewing	<input type="checkbox"/>	<input type="checkbox"/>
11. Pain related to grinding teeth during the night	<input type="checkbox"/>	<input type="checkbox"/>
12. Burning sensation in your mouth.....	<input type="checkbox"/>	<input type="checkbox"/>
13. Burning pain in the limbs (often associated with swelling or medication).....	<input type="checkbox"/>	<input type="checkbox"/>
14. Shooting pain/pins and needles down the limbs	<input type="checkbox"/>	<input type="checkbox"/>

RESULTS 1:

- We are showing data for 236 patients and 196 controls, matched by age and gender. Demographics: see table.
- In PD patients all assessed types of pain were present. Most frequent and least reported types of pain: see graph.



RESULTS 2:

- Differences between patients and controls reached significance level for joint pain, generalised whole body pain, dystonic, RLS related, nocturnal, bruxism and radicular pain (p<0.05, Mann-Whitney test).
- Dyskinetic and "off" related pain does not apply to non-PD controls and therefore were only assessed in patients.

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CONCLUSION: Interim results suggest the King's PD Pain Quest is a useful and the first self-completed tool complimentary to the King's PD Pain Scale for assessment of patient reported pain in PD, a key unmet need.